Improving Diagnostic Quality and Safety/Reducing Diagnostic Error: Measurement Considerations Web Meeting 6 Discussion Guide

Use Case 3: Cognitive Error—Information Overload

Information overload in complex or critically ill patients when the disease "signal" is too high

Overview/Clinical Context

Over the past two decades, there has been increasing complexity in both the content of clinical care (e.g., aging population, multiple chronic comorbidities, sicker hospitalized patients) and the delivery of that care (e.g., faster pace of care, more complex and disconnected teams, increased regulatory oversight, complicated electronic health records [EHR], novel technologies).[1] This comes in the context of an exponential expansion in the volume of new medical science that must be applied in healthcare. Meanwhile, the ability of humans to process large volumes of data has remained constant.[2] The sheer volume of information and how it is presented to clinicians can sometimes lead to errors, as clinician may have difficulty distinguishing important information from unimportant information.[3] In addition, the requirement to process a high volume of information may lead clinicians to miss a diagnosis that otherwise would have been readily apparent to the clinician if there were not as many sources of information and task overload.

One of the key underlying causes for these errors is the excessive cognitive load on the clinician. Cognitive load can be separated into intrinsic and extraneous loads. Intrinsic loads involve the complexity of the information itself.[4] For example, a clinician may experience high intrinsic load when caring for a multi-trauma victim in the ICU who is acutely hypotensive (i.e., low blood pressure). Even if the information is presented to a clinician simply and succinctly, sorting through the problem commands substantial cognitive energy. Extraneous load, by contrast, is the mental load imposed by the structure, organization, or presentation of the information and the mental processing capacity (i.e., working memory) it takes to reach the intended cognitive task. For example, extraneous load is high when EHRs are designed without considering human factors, such that finding relevant information (e.g., a pertinent radiographic test) requires searching in multiple locations.[5] Alternatively, there may be no graphical presentation of lab value trends, requiring clinician to notice the trend from the numeric values alone. Humans have a finite ability to manage cognitive load, so burdening their working memory with extraneous load leaves less available for intrinsic load. Creating clinical contexts and tools that have high extraneous load risks wastes precious working memory on unnecessary tasks (e.g., navigating the EHR) at the expense of intrinsic, mission-critical tasks (e.g., considering the full differential diagnosis for acute hypotension). Alternatively, additional cognitive load may be imposed on a clinician when a patient has searched for symptoms online resulting in the need to address a long list of concerning conditions that may have little clinical relevance to the accurate diagnosis.

Unnecessary tasks waste precious cognitive resources, but distractions and interruptions in the environment disrupt a clinician's focus, effectively shrinking the clinician's overall cognitive capacity to address both extraneous and intrinsic tasks.[6] This too can leave insufficient resources for tasks critical to

identifying an accurate diagnosis. A related phenomenon is alarm or alert fatigue – where clinicians receive so many warning signals or alarms (e.g., frequently beeping monitoring equipment or alert messages in the EHR) that they unconsciously or deliberately ignore them. For example, an alert for a true critical action lab value (e.g., a very high potassium level) might be ignored because there are similar alerts for all out-of-range lab results.[7]

Use Case 3 will focus on the types of errors that originate in situations where there is information overload. This includes high intrinsic load, high extrinsic load, excessive distraction, or a combination of all of these. The Use Case will address specific diagnostic challenges and causal factors that contribute to information overload and will consider global and granular solutions to prevent or mitigate errors resulting from information overload. The Use Cases also describe suggested approaches to measuring quality.

Case Exemplars

The case examples below demonstrate cognitive errors due to information overload that result in delayed or missed diagnosis.

Possible example 1

An Emergency Department (ED) physician is working an overnight shift in a busy urban hospital. Her patient load includes multiple patients at different stages in their clinical workup. One is an 85-year old woman with a history of chronic obstructive pulmonary disease (COPD) with home oxygen use and diabetes who came with shortness of breath, dizziness, and hypotension. She is awaiting laboratory and radiology results. Another patient is a 50-year old male with a history of diverticulitis and is three weeks post-operative colon resection surgery who presented with fever, nausea, vomiting, and abdominal pain for three days. He is awaiting his initial evaluation. The third patient is a 20-year old male with sickle cell anemia presenting with shortness of breath, chest pain, and fever, in addition to his typical sickle cell crisis pain in his bilateral legs. His chest x-ray shows a new infiltrate and his pain is uncontrolled. The fourth patient just arrived via ambulance to the trauma bay with a gunshot wound to his chest. He is a 30-year old man who is hypotensive and confused. He requires an emergent femoral central line and multiple blood transfusions. He is awaiting transport to surgery. Additionally, the physician is responsible for treating and evaluating low-acuity patients. She attempts to keep track of all of her patients and the multiple tests that result. She treats the abdominal pain patient with pain medication and orders a CT scan. She misses the CT scan result stating the patient has a possible small intra-abdominal abscess because she was so busy with other patients. In addition, the patient reports his pain has lessened, and he is discharged home. He returns the next day in septic shock (e.g. a much more serious infection) and an increased size of the abscess. His treatment requires immediate surgery to remove the infection, which could have been treated the day before with antibiotics and drainage through the skin.

Possible example 2

A 65-year old man with a history of hypertension and atrial fibrillation (i.e., irregular heartbeat) undergoes mitral heart valve repair due to stenosis. The complex open-heart procedure requires cardiopulmonary bypass and multiple blood transfusions. Post-operatively, he goes to the ICU for extensive, invasive monitoring. He is placed on the cardiac monitor with continuous blood pressure monitoring via an arterial line and had a triple-lumen central line in his subclavian vein. He has laboratory testing performed daily, including a complete blood cell (CBC) count, comprehensive

metabolic panel (CMP), and coagulation studies. His vital signs, obtained every two hours, and heart rhythm are checked daily and remain stable. The anion gap subtly increased daily with the trend reflecting early lactic acidosis. On post-operative day five, he becomes tachycardic and febrile. Blood cultures were obtained, and he is started on broad-spectrum antibiotics for bacterial sepsis. Despite the antibiotics, he continues to be tachycardic and febrile and blood cultures are obtained daily. A few days later the first blood culture grows *Candida albicans,* a yeast that causes a fungal infection, which the broad-spectrum antibiotics are not effective against. Since the early indication of lactic acidosis was missed and fungal sepsis was not initially considered, the delay in appropriate treatment led to his fungemia (i.e., fungus in the blood) infecting the repaired mitral valve and prolonged his ICU stay. The infected valve required additional surgery. Notably, the EHR has no trend analysis and there was no trigger to help identify this subtle trend in the anion gap and there was no protocol for considering multiple potential causes of sepsis.

Possible example 3

A 45-year old female presents with symptoms of intermittent generalized weakness to a primary care physician (PCP) for her first visit to the practice. She has a very complicated history with multiple medical and mental health comorbidities including insulin dependent diabetes, hypertension on three medications, rheumatoid arthritis on biological agents, as well as a longstanding history of pulmonary embolism on and off anticoagulants due to trouble with intermittent bleeding. She also has had multiple hospitalizations at different hospitals with multiple different imaging studies, including a brain MRI one year ago. During those hospitalizations, she saw different specialists and received multiple, sometimes conflicting, recommendations for treatment and additional diagnostic testing. There was turnover in her previous primary care practice and each time she returned, she saw a different clinician who attempted to integrate all the findings and recommendations; however, given the complexity of the information, no one was able to synthesize a coherent diagnostic approach. At her new primary care practice, she brings all previous records, including past primary care and specialist clinic notes, hospital discharge summaries, and previous imaging study reports. The new PCP attempts to review all the information but is unable to process all of it. On examination, the patient appears chronically, but not acutely, ill. Over the next six months, the patient's symptoms increase, and she has multiple clinic visits and normal laboratory testing. The patient eventually has an evaluation by a neurologist who recommends a brain MRI. While reviewing the imaging study, the neurologist reviews her previous brain MRI via a health information exchange. He notes the patient has progressive demyelinating findings and diagnoses multiple sclerosis (MS). The old MRI results that showed some concern for demyelinating disease were included in her records she provided her new PCP, but were not reviewed due to the large amount of information provided. This resulted in a delay in follow up with a neurologist and a subsequent delay in diagnosing MS.

Diagnostic Challenges and/or Causal Factors

The case exemplars demonstrate a class of cognitive errors resulting in delayed or missed diagnosis, some of which can result in serious harms. Each case exemplar highlights diagnostic challenges and points to causal factors that likely contributed to the error.

Diagnostic Challenge/Causal Factors
Clinician Factors: • Physical fatigue (e.g., overnight shifts, lack of sleep) • Mental fatigue (e.g., long shifts with many complex patients) • Alarm fatigue • Distractions • Decreased ability to handle high cognitive load due to limited clinical experience or older clinician age
Systems Factors: • Poor organization of information within the EHR • Process complexity (e.g., multiple steps and processes to find the correct consultant or on-call provider) • Interruptions (e.g., busy environments with constant interruption of new information and requests) • Multiple care settings and providers involved in the patient's care • Information complexity (e.g., information is too detailed and complex, or there is diverse and wide-ranging information) • Ambiguous information (e.g., higher levels of ambiguity require higher levels of cognitive load to discriminate between what is known and unknown)
Condition/Disease Factors: • Clinical complexity (e.g., findings are masked by the patient's complex clinical state)

Committee Discussion Questions:

1. Are any causal factors/diagnostic challenges missing?

Solutions

Various stakeholders, including clinicians, researchers, and payers, can help implement, develop, or incentivize solutions to overcome the error(s).

Possible Solutions	
Solution	**Leverage technology as a tool to manage complex information**

Possible Solutions	
Process	• Enable technology to identify important changes in clinical information o Collaborate with EHR vendors and IT teams to understand the capability of the EHR to perform data visualization methods and trend clinical values (e.g., vital signs, input and output, laboratory test results, pain medication utilization, invasive device usage, etc.) o Educate clinicians on the capability of EHRs to perform data visualization methods and trend analyses o Use AI to recognize data patterns to support identification of clinically relevant findings • Increase the usability of EHRs o Partner with EHR vendors to identify future opportunities for data visualization methods that improve the usability of EHRs o Use a human factors engineering approach when designing EHRs and adding new features o Engage frontline staff and end-users in discussions and focus groups with EHR vendors to help understand how features are currently being used and to identify opportunities for improved usability o Request that vendors perform education with frontline staff to share strategies for maximizing the capacity of the EHR o Build multidisciplinary teams to analyze current EHR notifications and make recommendations to reduce notifications that do not increase patient safety o Examine current EHR notifications and identify opportunities to increase clinical salience of the notifications
Solution	**Support clinicians in managing large and/or complex patient loads**

Possible Solutions	
Process	• Employ a team approach to help distribute and/or offset the cognitive load on a single clinician o Engage multidisciplinary team members with varied expertise to support clinical decision making o Understand current patient load and create thresholds and capacity limits for a single clinician o Limit the number of patients cared for by a single clinician based on data findings o Rotate or shift repetitive tasks at pre-identified scheduled intervals o Reduce the number of extraneous tasks performed when finding information to enable clinicians to focus on clinical tasks (i.e., task offloading) • Increase access to mechanisms and tools that help clinicians process complex clinical information o Develop diagnostic algorithms and/or protocols for specific clinical circumstances that address known pitfalls in diagnoses o Use simulation training to prepare clinicians for managing situations with high cognitive load and large amounts of information o Increase access to specialists through telemedicine, especially in rural settings o Provide access to online textbooks and/or online journals o Provide access to diagnostic tools, such as differential diagnosis generators or diagnostic reminder systems o Create an easily accessible tool that contains information for on-call clinicians and specialists that can assist with complex cases or large patient loads
Solution	**Provide patients opportunities to help manage information**
Process	• Create opportunities for patients to highlight important clinical information o Encourage patients and families to actively monitor their own care and escalate issues as they arise • Ensure patients understand what diagnoses are being considered and what has been ruled out o Explain to patients what diagnostic tests are being performed o Communicate frequently with patients about updates to the differential diagnosis when certain diagnoses have been ruled out o Provide education materials that are suitable for patients and their families about their diagnosis. o Provide patient access to medical records

Committee Discussion Questions:

1. Are any solutions missing?
2. What specific actions can payers take to support implementation of the solutions?
3. What specific actions can researchers take to identify and test new solutions, and build an evidence base to support existing solutions?
4. How can the solutions be operationalized?

Measurement Considerations for Use Case 3

In order to ensure that clinicians and healthcare systems reduce the likelihood of misdiagnoses of complex or critically ill patients when the disease "signal" is too high, there are a variety of approaches to measuring quality. Measure developers can use these concepts and approaches to develop and test new clinical quality measures, either as process measures to support diagnosis or as clinical outcomes. Payers can use these measures in improvement and payment programs to incentivize adoption of diagnostic best practices and improve quality of care.

Measurement Approach	Measure Concepts	Rationale
Assess the usability of EHR platforms by users	• Clinician-reported assessments of usability • Presence of data visualization methods that meet quality standards within the EHR	• Measuring the usability of EHRs, such as the presence of data visualization methods and other tools to identify EHRs that are more successful in managing information and those with opportunities to improve usability, in particular to display and management of complex information
Measure clinician productivity as a proxy for cognitive load	• Number of patients seen per hour by a clinician	• Gathering information on the number of patients seen by a single clinician in a given time frame and also during times of peak demand may serve as a proxy for understanding the burden, clinical load, and/or cognitive load on particular clinicians • Analyzing information on clinical load and diagnostic errors may help inform if certain thresholds should be in place to help manage cognitive load
Measure the time to identify important clinical events	• Time to detection of important clinical events (e.g., sepsis)	• Understanding the time it takes to detect important clinical events will help identify opportunities where misdiagnoses are occurring, as well as provide data for root-cause analysis and follow-up to pinpoint remediable causes of delays

Measurement Approach	Measure Concepts	Rationale
Assess data sharing	• Rate of participation in a health information exchange	• Participation in a health information exchange supports the use of data to improve accessibility of information and reduce diagnostic errors
Assess patients' perceptions of if they are part of the diagnostic team	• Patient-reported perceptions of patient input into the diagnostic process	• Gathering information directly from the patient may be a useful way to measure if a patient feels that his/her opinions are heard, and he/she is part of the diagnostic team
Measure relational coordination	• Coordination of Care Index (COCI)[8]	• Measures of relational coordination, which focus on coordination and communication of teams, could serve as a proxy for if information and tasks are being successfully addressed by the team

Committee Discussion Questions:

1. Are any measurement approaches missing?
2. What specific actions can developers and payers take to facilitate the measurement solutions?

Use Case 4: Cognitive Error – Dismissed Patient

Prolonged diagnostic odyssey for chronic symptoms when the disease "signal" is minimal or ignored

Overview/Clinical Context

Patients with uncommon conditions, or unusual presentations of more common conditions, often experience long diagnostic delays in the assessment of chronic symptoms that are mild, non-specific, or evolving slowly.[9] If an initial search identifies no "objective" abnormalities that correspond to the patient's symptoms, the patient may be labeled as having "medically unexplained symptoms" and the search may be terminated. If the patient or clinician, insists on pursuing additional testing, the patient may begin a prolonged "diagnostic odyssey" in which the patient visits multiple specialists in search of a diagnosis.[10] If no diagnosis is found despite substantial amounts of testing, the patient may be dismissed as having functional symptoms, somatization, or hypochondriasis; alternatively, the patient may be placed in a "wastebasket" diagnostic category without definitive diagnostic tests (e.g., chronic fatigue

syndrome).[11] After such a diagnosis is given, additional symptoms may be ignored by clinicians or attributed to the original diagnosis.

Some delays occur because a condition is rare and indolent, and therefore unknown or unfamiliar to the patient's clinician. For example, hereditary angioedema (HAE) is a rare, genetic condition that involves periodic swelling of the face, airway, extremities, and abdomen and has a prevalence of 1 in 50,000.[12] Diagnostic delays commonly occur in HAE patients, and the average time from first symptoms to diagnosis is greater than two years, with some delays in diagnosis taking up to 20 years.[13] Similarly, non-classic manifestations of common diseases, such as migraine, may be known only in narrowly focused subspecialties (e.g., recurrent dizziness caused by vestibular migraine known to neuro-otologists).

Non-specific symptoms, such as fatigue or chronic low-grade abdominal pain, are especially prone to diagnostic odysseys because the symptoms cross many specialty lines and often multidisciplinary clinical communication is lacking. Diagnostic delays can lead to harm from failure to treat an underlying disorder or from the adverse effects of empiric symptomatic therapies.[14] The odyssey itself can exact a major psychological and financial toll on the patient, family, and/or caregivers.[15]

While most patients with symptoms deemed "medically unexplained" in the modern era do not develop an overt medical cause in follow-up, an estimated 1-5 percent do. Whether they turn out to be misdiagnosed or not, the psychological impact of this "non-diagnosis" diagnosis on patients can be substantial.[16] When patients do finally achieve a diagnosis, they often describe feeling dismissed or not listened to during their odyssey. In some cases, they key to the correct diagnosis was, in fact, something the patient tried to say but was not heard or appreciated by the clinician. In other cases, affective bias may have contributed. This may manifest as clinicians becoming angry or frustrated with the patient, failing to listen to or hear from the patient, and/or giving up on the patient.

Use Case 4 will focus on the types of errors that originate in patients with chronic, unexplained symptoms. The Use Case will address specific causes for diagnostic odysseys that occur when patients are dismissed, and will consider global and granular solutions to prevent or mitigate these types of errors. The Use Cases also describe suggested approaches to measuring quality.

Case Exemplars

There are a variety of clinical examples where patients are dismissed and long, diagnostic odysseys may occur, leading to diagnostic delays and poor outcomes. The case examples below demonstrate how errors due to dismissed patients result in delayed or missed diagnosis.

Possible example 1

A 23-year-old female has a longstanding history of three years of intermittent abdominal pain, bloating and diarrhea. She is uninsured and goes to the emergency department when she has symptoms. Over the initial three years of her symptoms, she has had six CT scans that have been normal and has been admitted to the hospital twice for the condition for observation, with no clear diagnosis of a cause of her symptoms. Between her multiple visits, she explores the internet for information about her symptoms to try to identify what is causing them. She learns about celiac disease and believes it perfectly fits her symptoms. She brings this up to her clinicians at subsequent appointments, but the clinicians continually disregard her self-diagnosis and respond that there are many causes of abdominal pain and they must explore all possible diagnoses. After each visit, she is referred to see a

gastroenterologist as an outpatient but has never made it to an appointment because the clinicians have asked for payment upfront before she is seen, which she states she cannot afford. She finally is able to obtain health insurance through her a new job and sees a gastroenterologist. The gastroenterologist conducts an endoscopy and additional blood testing, and she is ultimately diagnosed with celiac disease (i.e., a gluten allergy) and is able to improve her symptoms through diet modifications.

Possible example 2

A 40-year old female with no medical history developed widespread muscle pain, tenderness, and numbness with increased fatigue, vague abdominal pain, and depression. She sees her PCP who diagnoses her with fibromyalgia and prescribes anti-inflammatory and muscle relaxant medication. She also sees several other providers including a psychiatrist, a chiropractor, and a massage therapist. Her symptoms do not improve, and she decides to see a rheumatologist, as well a neurologist, who treat her symptoms as functional. She presents her history and medical records. Neither specialist considers an alternative diagnosis and agrees with the PCP's diagnosis of fibromyalgia. One morning the patient wakes up with more severe abdominal pain. She goes to the Emergency Department where she is evaluated for possible appendicitis with a CT. Instead of appendicitis, they find that she has metastatic ovarian cancer, which was the cause of her symptoms all along.

Possible example 3

A 45-year old woman with a history of anxiety and schizoaffective disorder presents to multiple Emergency Departments with reports of longstanding, intermittent headaches over a one-year period. She states she has a history of migraines. She is homeless and has been to this Emergency Department many times, and is often dismissed by the clinicians due to her history and frequent visits. Each time she goes to the Emergency Department, she usually receives a cursory physical examination, which is consistently normal, is given acetaminophen, and is referred to a social worker and told to follow-up with a PCP. One day, she presents with a fall with a scalp hematoma and receives a head CT. The head CT does not demonstrate intracranial bleeding, but does demonstrate a moderate-sized brain mass in her medial temporal lobe and midline shift which was the cause for her indolent headaches that was missed during her multiple ED visits.

Diagnostic Challenges and/or Causal Factors

The case exemplars demonstrate a class of cognitive errors resulting in delayed or missed diagnosis, some of which can result in serious harms. Each case exemplar highlights diagnostic challenges and points to causal factors that likely contributed to the error.

Diagnostic Challenge/Causal Factor
Clinician Factors: • Lack of PCP who synthesizes information from multiple sources • Tendency to undervalue patients' knowledge and contributions to the diagnostic process • Cognitive biases, including implicit bias, confirmation bias, overconfidence, and affective bias • Failure to explain to the patient diagnostic tests previously performed and diagnoses that have already been ruled out

Diagnostic Challenge/Causal Factor
System Factors: • Lack of interoperability across EHRs • Over-emphasis and over adherence to protocols • Multiple care settings and providers involved in the patient's care
Condition Factors: • Rarity of the condition • Condition may not be diagnosable with commonly used tests • Non-specific nature of symptoms

Committee Discussion Questions:

1. Are any causal factors/diagnostic challenges missing?

Solutions

Various stakeholders, including clinicians, researchers, and payers, can help implement, develop, or incentivize solutions to overcome the error(s).

Possible Solutions	
Solution	**Enhance opportunities for patient engagement through education and training**

Possible Solutions	
Process	• Provide education to support clinicians actively engaging patients and families as part of the diagnostic team o Require clinician education on patient-centered diagnostic decision-making and shared decision making o Create diagnostic checklists with items that pertain to getting input from the patient and/or family and ensuring patient and family concerns are addressed o Share information about diagnostic tests performed and diagnoses ruled in or out with patients to support their own understanding of the diagnostic process • Support clinicians in overcoming common biases that may limit their ability to hear the perspectives of patients o Educate clinicians on common types of biases that contribute to dismissing the perspectives of a patient (e.g., affective bias) o Support clinicians in identifying mechanisms to identify and overcome bias, such as performing a "gut check" for feelings of anger, frustration, or hopelessness when managing a complex patient o Create protocols for initiating consultations and/or second opinions (e.g., repeated visits for the same symptom with no explanation) • Encourage clinicians to act early on the concerns voiced by patients and families o Support the use of early referrals for genetic counseling, specialist care, and other high-risk situations o Educate clinicians that protocols are a tool to support accurate diagnoses but that deviations from protocols may occur based on clinical presentation and/or patient needs o Engage patients to share stories with clinical teams where diagnostic errors occurred when the patient concerns and input were not listened to
Solution	**Empower patients to raise concerns and share their perspectives**

Possible Solutions	
Process	• Invite patients to be part of the diagnostic team o Request input directly from patients and families when trying to understand the clinical picture o Provide frequent opportunities for patients and families to share important information and/or raise concerns o Offer feedback to patients to reinforce how the information shared helps contribute to an accurate and timely diagnosis o Use shared decision making to co-create a diagnostic plan together with patients and families o Use signage throughout the organization that encourages patients to speak up • Ensure patients understand what diagnoses are being considered and what has been ruled out o Explain to patients what diagnostic tests are being performed o Communicate frequently with patients about updates to the differential diagnosis when certain diagnoses have been ruled out o Provide patient access to medical records • Engage the Patient and Family Advisory Council (PFAC) o Partner with the PFAC to identify and understand opportunities to increase patient engagement in the diagnostic process o Identify new opportunities to engage the PFAC in co-designing activities that promote timely and accurate diagnoses o Offer education (e.g., materials, online classes, support groups) for how patients can be their own advocate • Engage patients who have experienced diagnostic odysseys to help prevent diagnostic errors in the future o Create processes to support patients initiating a retrospective case review, or root cause analysis, of diagnostic odysseys and/or errors o Connect patients who have experienced diagnostic odysseys to participate on PFACs and Quality Committees to facilitate continuous improvement and learning o Enable patients to participate in Morbidity & Mortality conferences to describe the impacts of their concerns being dismissed and the diagnostic error they experienced o Encourage patients with conditions that commonly experience diagnostic odysseys to participate in support groups with other patients to support learning and improvement
Solution	**Identify opportunities for technology and data to recognize potential diagnostic odysseys**

Possible Solutions	
Process	• Use technology as a learning tool o Perform data analytics to identify known diagnostic pitfalls o Use information on known diagnostic pitfalls to identify opportunities for targeted improvement opportunities o Use AI and/or machine learning to detect patterns for diagnostic odysseys in EHRs and/or claims data o Leverage AI analytics as learning opportunities and share feedback to clinicians, when possible • Use data to understand the impacts of diagnostic odysseys o Partner with payers to use claims data to retrospectively analyze the time and cost impacts of diagnostic odysseys o Use claims data to pinpoint opportunities for improvement in the diagnostic process o Harvest data obtained from patient concerns and surveys to identify patterns and trends to inform organization-specific solutions o Partner with data-focused organizations to support measurement and datamining as a performance improvement tool • Increase information sharing and interoperability across EHRs and settings o Build and support regional health information exchanges o Ensure access to patient information across health systems through information sharing requirements

Committee Discussion Questions:

1. Are any solutions missing?
2. What specific actions can payers take to support implementation of the solutions?
3. What specific actions can researchers take to identify and test new solutions, and build an evidence base to support existing solutions?
4. How can the solutions be operationalized?

Measurement Considerations for Use Case 4

In order to ensure that clinicians and healthcare systems reduce the likelihood of patients experiencing diagnostic odysseys, there are a variety of approaches to measuring quality. Measure developers can use these concepts and approaches to develop and test new clinical quality measures, either as process measures to support diagnosis or as clinical outcomes. Payers can use these measures in improvement and payment programs to incentivize adoption of diagnostic best practices and improve quality of care.

Measurement Approach	Measure Concepts	Rationale
Assess when team-based approaches are initiated	• Presence of a protocol for escalation of the diagnostic approach (e.g., second-opinions, consults, and/or additional testing) for patients with continued undiagnosed symptoms	• Using team-based approaches to diagnosis, including second-opinions, expert consults, and more expansive testing will help reduce the likelihood of a single clinician's biases closing off potential diagnostic pathways and/or dismissing the patient's concerns and perspectives
Measure the time to diagnosis for rare conditions	• Days from original patient chief complaint until final, accurate diagnosis	• Measuring the time to diagnosis for rare conditions will help increase understanding of the delays that patients experience and will help identify changes and improvements over time • Understanding the diagnostic delays that occur and how they impact treatment delays may help identify specific opportunities for improvement and efficiency in the diagnostic process
Measure the total cost of the diagnostic odyssey	• Total cost of the diagnostic odyssey	• Measuring the total cost of a diagnostic odyssey experienced by the patient will help increase understanding of the impacts of delayed diagnoses and diagnostic errors
Measure the volume and impact on diagnostic testing	• Number of consultations and/or second opinions	• Using a balancing measure will help understand how new protocols and processes for escalation of care for patients with undiagnosed symptoms are impacting the volume of consultations, second opinions, and/or diagnostic testing
Assess patient experience with diagnostic odysseys	• Patient-reported satisfaction with the diagnostic process	• Gathering information directly from the patient may help understand the patient-level impacts of diagnostic odysseys and how these experiences share their perception of the healthcare system

Committee Discussion Questions:

1. Are any measurement approaches missing?
2. What specific actions can developers and payers take to facilitate the measurement solutions?

References

[1] Stange KC. The problem of fragmentation and the need for integrative solutions. Ann Fam Med. 2009;7(2):100–103. doi:10.1370/afm.971

[2] Wyer, R. S., Jr. (2012). A theory of social information processing. In P. A. M. Van Lange, A. W. Kruglanski, & E. T. Higgins (Eds.), Handbook of theories of social psychology (p. 156–177). Sage Publications Ltd.

[3] Engineering a learning healthcare system: A look at the future: Workshop summary. Washington, DC: The National Academies Pres

[4] Fraser KL, Ayres P, Sweller J. Cognitive Load Theory for the Design of Medical Simulations. *Simul Healthc*. 2015;10(5):295–307. doi:10.1097/SIH.0000000000000097

[5] Melnick ER, Dyrbye LN, Sinsky CA, et al. The Association Between Perceived Electronic Health Record Usability and Professional Burnout Among US Physicians. Mayo Clin Proc. 2020;95(3):476–487. doi:10.1016/j.mayocp.2019.09.024

[6] Sanderson P, McCurdie T, Grundgeiger T. Interruptions in Health Care: Assessing Their Connection With Error and Patient Harm. Hum Factors. 2019;61(7):1025–1036. doi:10.1177/0018720819869115

[7] Cvach M. Monitor alarm fatigue: an integrative review. Biomed Instrum Technol. 2012;46(4):268–77. doi: 10.2345/0899-8205-46.4.268.

[8] Pollack CE, Hussey PS, Rudin RS, Fox DS, Lai J, Schneider EC. Measuring Care Continuity: A Comparison of Claims-based Methods. Med Care. 2016;54(5):e30–e34. doi:10.1097/MLR.0000000000000018

[9] Sawyer SL, Hartley T, Dyment DA, et al. Utility of whole-exome sequencing for those near the end of the diagnostic odyssey: time to address gaps in care. Clin Genet. 2016;89(3):275–284. doi:10.1111/cge.12654

[10] Grier J, Hirano M, Karaa A, Shepard E, Thompson JLP. Diagnostic odyssey of patients with mitochondrial disease: Results of a survey. Neurol Genet. 2018;4(2):e230

[11] Carson A, Stone J, Hibberd C, et alDisability, distress and unemployment in neurology outpatients with symptoms ‘unexplained by organic disease’Journal of Neurology, Neurosurgery & Psychiatry 2011;82:810-813.

[12] Weis M. Clinical review of hereditary angioedema: diagnosis and management. Postgrad Med. 2009;121(6):113–120

[13] Zanichelli A, Magerl M, Longhurst HJ, et al. Improvement in diagnostic delays over time in patients with hereditary angioedema: findings from the Icatibant Outcome Survey. Clin Transl Allergy. 2018;8:42. Published 2018 Oct 12. doi:10.1186/s13601-018-0229-4

[14] Hennekam R.C.M. Care for patients with ultra-rare disorders. Eur. J. Med. Genet. 2011;54:220–224.

[15] Carmichael N, Tsipis J, Windmueller G, Mandel L, Estrella E. "Is it going to hurt?": the impact of the diagnostic odyssey on children and their families. J Genet Couns. 2015;24(2):325–335.

[16] Carr S. Unexplained Symptoms: When Diagnostic Uncertainty Becomes a Diagnosis. *Society to Improve Diagnosis in Medicine*. https://www.improvediagnosis.org/improvedx-july-2019/unexplained-symptoms-when-diagnostic-uncertainty-becomes-a-diagnosis/. Last accessed February 2020.